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ABSTRACT

This guide describes Community ChoiceWork, an approach to directly involving citizens in issues that affect them (in this case, HIV/AIDS). It is intended help citizens frame and deliberate on an issue of concern that has no clear solution. After explaining what Community ChoiceWork is, the guide discusses what it has to do with HIV/AIDS. Next, it presents the Community ChoiceWork process in a step-by-step manner: (1) "Getting Started" (agreeing on the intended goal and ensuring group commitment); (2) "Stakeholder Analysis Month One" (e.g., identifying major stakeholders and selecting members for the ChoiceWork committee); (3) "Mapping and Naming the Problem and Framing Choices" (e.g., grouping like concerns and perspectives, listing actions, and naming the problem); (4) "Finalize the Framework Month Three" (testing the framework and writing a title and writing the discussion guide); (5) "Deliberating and Setting Direction Month Four" (coordinating and moderating public forums and setting direction in public forums); (6) "Reporting Back Month Five" (taking notes during forums and compiling reports from all forums); (7) "Creating an Action Plan Month Six" (community mobilization, community priority setting, and advocacy campaigns); and (8) "Taking Action." An appendix presents illustrative discussion guides. (Contains 29 references.) (SM)

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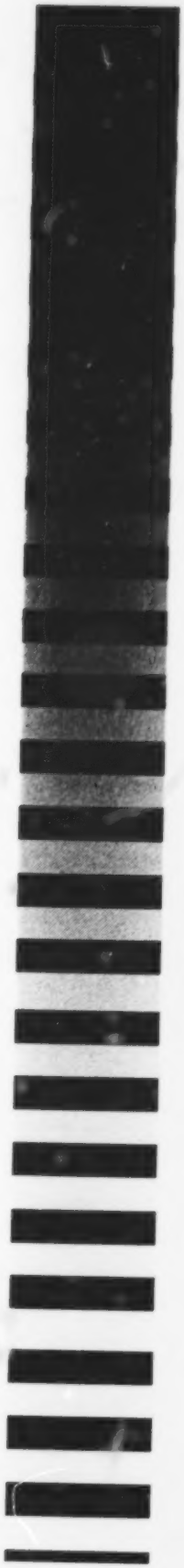

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COMMUNITY CHOICEWORK

CITIZEN DELIBERATIONS ON ISSUES RELATED TO HIV/AIDS

January 2002
ACADEMY FOR EDUCATIONAL DEVELOPMENT

UD 035 024

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For more information about facilitating the ChoiceWork process, contact:
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The main author of the manual is Chanya Charles of the Academy for Educational Development. Michael Kott of the Academy is the project director. The guide also benefited from advice and reviews from Frank Beadle de Palermo, Philippa Lawson, Melissa Werner, and Jackson Peyton of AED's Center for Community-Based Health Strategies and Andrea Usiak of AED's Civil Society Initiatives.

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AED's Civil Society Initiatives prepared this document under a cooperative agreement with the Kettering Foundation.

Preface

Community ChoiceWork is an approach to directly involve citizens in issues that affect them. This guide is the outcome of a collaboration between the Kettering Foundation and the Academy for Educational Development (AED). The Kettering Foundation has been a pioneer in promoting the use of deliberative democracy with citizen groups around the United States and overseas. Kettering's philosophy is that for democratic politics to work as it should, the public has to act. And before they can act, the public must make informed choices about issues of concern to them. Public deliberation is one way to decide how to act. Thus, Kettering, through the National Issue Forums in the United States, supports gatherings around the country where people can deliberate on issues that are of concern to the public.

AED's international work in democracy building and civil society strengthening focuses on non-governmental organization (NGO) development; advocacy and outreach; technical assistance and training; sustainability strategies; grant-making; and analysis and evaluation.

AED is well positioned to create and implement solutions to the HIV/AIDS epidemic. With a global staff of over 1000 professionals, AED experts on behavior change, communications, capacity building, policy development, community and school mobilization, and research and evaluation are personally committed to tackling one of the greatest health crises of our times. Our work in over 100 countries positions us to move rapidly, and with sensitivity, to local situations. Our experience working with government agencies, multilateral banks, foundations, and corporations gives us the knowledge we need to address the complexities of the epidemic. Our partnerships with international, national, and community organizations have helped us see that we must all work together in the fight against AIDS.

Mutual respect between the Kettering Foundation and AED led to a collaboration between the organizations to host training workshops in the deliberative approach for international NGO representatives.

AED and Kettering believe that public deliberations build social capital. That is, the process of coming together around common problems changes the way people relate to one another. This process can strengthen bonds within a community. We also believe that these strengthened bonds can help improve a community's health, environment, economy, and reduce stigma and discrimination associated with HIV/AIDS.

Community ChoiceWork is a tool adapted from the Kettering Foundation's deliberative democracy process and AED's Center for Community-Based Health Strategies, (CCHS) work with community planning processes. Increased citizen participation and civic involvement not only make communities more democratic, but also improve people's capacities to sustain improvements in their quality of life over time. The collaboration between AED and Kettering is based on the notion that development work in any sector is more effective when direct engagement of citizens and stakeholders is included in all stages of the process. Engaging citizens in discussions of issues that affect them can strengthen the bonds and abilities within a community to deal with those issues. This can lead to improved health, environment, and economic conditions within the community.

Community ChoiceWork is intended to lead communities to action by having citizens frame and deliberate an issue of concern that has no clear solution. This manual is meant to help people make better decisions together about issues that affect them directly. It presents the Community ChoiceWork process in a step-by-step manner. It is intended for activists from groups, community-based organizations (CBOs), NGOs, and private voluntary organizations (PVOs). NGOs that are working on behalf of their citizen constituents need new tools to assist them in engaging citizens directly. Our hopes are to direct the attention of these organizations to the importance of citizens engaging on their own terms and to provide them with tools that facilitate this type of action. Community ChoiceWork is one of these tools.

We hope that readers will share the manual with others in their organizations or with whom they work, and recognize the potential of using this process to achieve their desired results. A more detailed curriculum to facilitate the process is currently being developed.

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Community ChoiceWork
Academy for Educational Development

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What is Community ChoiceWork?

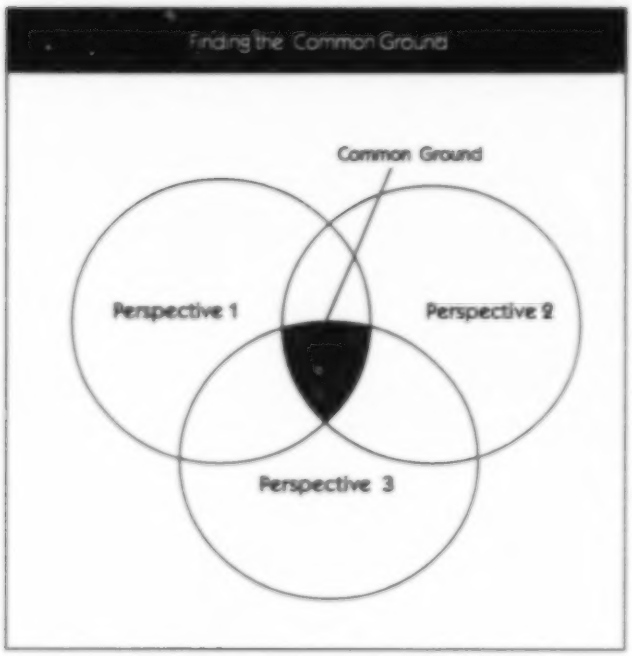
Community ChoiceWork is common sense. It is not some complex technical methodology that only experts can carry out. It is the same process that we all use to make personal decisions in our daily lives. The only difference is that the process is used by citizens to make decisions together for a collective group.

Community ChoiceWork is based on a process of deliberation leading to action. Deliberation emphasizes the idea of thinking through the complexities of a problem and weighing all the options for solving it. This is very different from a debate, which presents two sides of a problem with the assumption that one is right and the other is wrong (see Table 1). Deliberation is also different from unstructured dialogue in that it leads to decisions and action.

Table 1
Debate and Deliberation

Debate	Deliberation
...search for glaring differences	...search for common principles
...search for weaknesses in another position	...search for strength in each position
...involves countering the other's position	...assumes that many people have pieces of an answer to a workable solution
...calls for investing wholeheartedly in your beliefs	...you temporarily suspend your beliefs
...is oppositional and seeks to prove the other wrong	...is collaborative and seeks common understanding
...the goal is winning—often only for a short-term advantage	...the goal is common ground for action, which is the basis for consistent policy
...you listen to find flaws and counter-arguments	...you listen to understand and find meaning in agreement
...defends assumptions as truths	...reveals assumptions for reevaluation
...you submit your best thinking and defend its rightness	...you submit your best thinking in order to improve it

Community ChoiceWork is a useful tool when there are diverse groups with different needs, priorities, beliefs, and attitudes, as is the case in the majority of communities affected by AIDS. Community ChoiceWork involves finding the common principles that emerge from concerns of diverse groups. While groups may have different entry points for their concerns, they will only truly engage with one another if they have a stake in the common ground. The process itself is not exciting on paper. It is the engagement of diverse groups that is exciting. Community ChoiceWork depends on active participants whose passion for the issue at hand seeps into the process to create a dynamic methodology.



This document outlines the eight steps of the ChoiceWork process and provides stories of how it has worked in various places. The objective is to provide a basic understanding of the mechanics of the approach. It is up to you to add passion, enthusiasm, commitment to inclusion, and action for the HIV-related issue being worked on to make Community ChoiceWork a success. As mentioned in the preface, a curriculum for facilitators of the ChoiceWork process is being developed. Contact the Academy for Educational Development for more information.

Surviving Breast Cancer

In the United States, breast cancer is the leading killer of American women aged 35 to 54. Yet, it is a disease that can be treated and survival rates are high for those whose cancer is caught in time. The deliberative process was used in rural west Alabama, where breast cancer is the leading cause of death among all women. The process identified three ways in which a community might deal with this problem: 1) provide widespread public education; 2) create a network of support groups so that women can help one another; and 3) ensure an informed, active clergy who could have a strong influence on women's health-seeking behavior and overall death rates.

When Should You Use Community ChoiceWork?

ChoiceWork is a process to be used when there is a burning issue affecting multiple players within a community and there is no clear solution on how to address the issue. You do not need ChoiceWork if there is only one path to take. You do not need ChoiceWork if the community is already unified regarding the action to be taken. This methodology is not all inclusive or the perfect answer to all your problems. It is helpful when there is real tension among groups over an issue. It does provide an excellent way to bring a diverse set of actors together to move forward with a common agenda.

Who Should Be Involved In Community ChoiceWork?

The ChoiceWork process should involve a wide variety of people representing different points of view. No matter who you are—a large PVO or a small CBO—the big question is: who is the community in Community ChoiceWork? Many of the NGOs working on HIV/AIDS would identify the community as the same group of people who have been working on the issue for years. In ChoiceWork, the community is much greater than this. The community includes all the people affected by, or who can affect, the issue being discussed. And, for HIV/AIDS, that means just about everyone. Thus, it is important to find ways to hear the viewpoints from multiple actors, especially those who have not traditionally been involved in your work. You may have to step back from time to time and ask: "Who is missing from the room? What would that person think about this?"

Why Should You Use Community ChoiceWork?

People involved in international development work today have a multitude of participatory approaches to choose from. The question is which ones to use when. One approach is not necessarily better than another. Deciding which tool to use depends on the diversity of the stakeholders, context, the objectives, and the resources available.

Community ChoiceWork can be helpful when the goals are to:

- generate community action
- design community-driven programs
- advocate for policy change and implementation

For the first goal—generate community action—ChoiceWork can help a community decide what action it needs to take to improve a particular situation. For the second goal—design community-driven programs—the ChoiceWork process can ensure that groups, including NGOs, are creating

programs that meet the needs of their constituents. And, for the third goal—advocate for policy change—the ChoiceWork process can develop wide-based support to legitimize an issue and create alliances for action.

What Is the Rationale Behind Community ChoiceWork?

The main idea behind this approach is that action supported by multiple groups will have a greater impact than action taken by individual groups. ChoiceWork provides an opportunity for people with differing views to find common ground and move forward together. It results in changing dynamics among different actors and the construction of different alliances.

The rationale behind Community ChoiceWork is that:

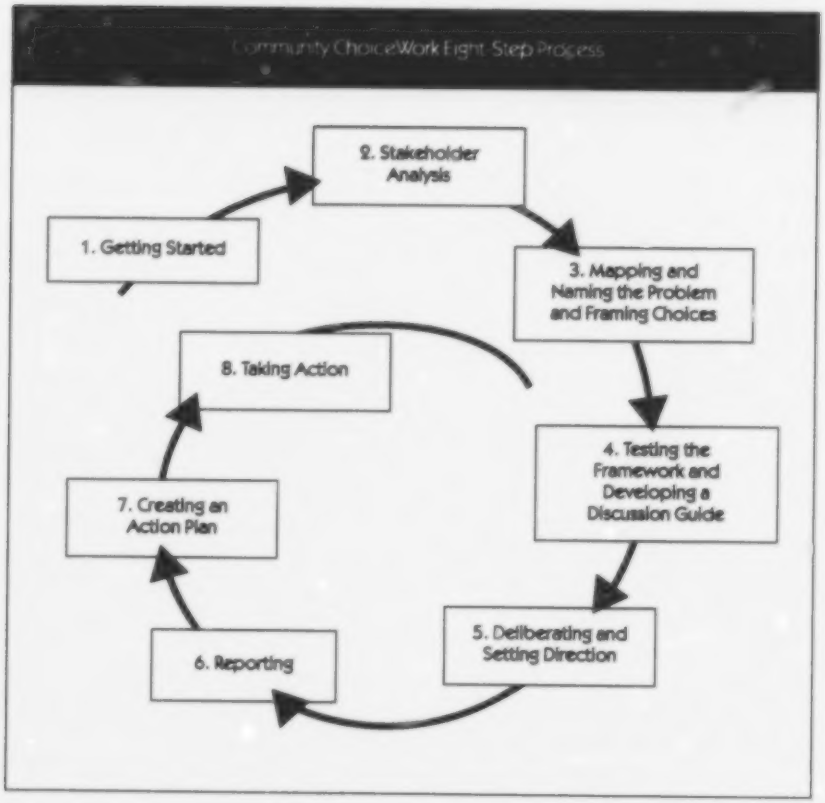
- Implementation of policies and programs requires public action.
  - Public action requires people making choices together.
    - Policy and programmatic choices require public deliberation over what is valued by communities.
      - Deliberation produces public judgment, which gives shared purpose and direction to public action and legitimacy to government action when it reflects public judgment.

Public knowledge is a shared understanding of the issue of importance to the community and identification of common ground for action. Finding common ground requires a sharper definition of the public's interest, a shared sense of purpose and direction, and the identification of a range of actions that the public would support.

Wait A Minute – It Won't Be Easy...

Community ChoiceWork is a participatory process that aims to allow greater deliberation of policies and their practical implementation through the inclusion of a variety of social actors in consultation, planning, and decision-making. Do not mislead the public into thinking that they have a voice in the decision-making process if a decision has already been made. At the same time, ensuring that all voices are heard does not mean that people will agree on the same direction for action. In fact, the voices will represent differing opinions and strongly held values and approaches. Community ChoiceWork does not aim to change these opinions, but rather to assist people in finding common ground among the various perspectives.

The Community ChoiceWork process assumes that the group organizing the effort truly values the public's voice. It moves beyond what an organization can do for a community to how it can catalyze a community to take actions for itself. The ChoiceWork process allows an organization to create space for citizens to realize their capacities. Time is required to create this space so communities can engage in dialogue and arrive at common ground for action. The eight-step process described in this manual suggests a six-month time frame. However, the process could take less or more time. In addition, the process is not really over once the forums have been held, reports written, and an action plan put in place. The action needs to happen. It is the responsibility of all the players involved—citizens, businesses, religious institutions, organizations, and government—to implement the strategy that develops from the ChoiceWork process.


Community ChoiceWork Eight Step Process
1. Getting Started
2. Stakeholder Analysis
3. Mapping and Naming the Problem and Framing Choices
4. Testing the Framework and Developing a Discussion Guide
5. Deliberating and Setting Direction
6. Reporting
7. Creating an Action Plan
8. Taking Action

What does Community ChoiceWork Have to do with HIV/AIDS?

For the past 20 years, the deliberative dialogue approach promoted by the Kettering Foundation focused on its impact on democracy. It was believed that through structured or systematic dialogue, citizens would be better informed about the multiple dimensions of a public issue and could therefore make educated decisions related to it. In the history of the development of democracies, indirect representation of citizens by their elective representatives has emerged as the predominant form of this system of government. Citizens vote to elect their representatives in lieu of deliberating and voting on substantive issues, except in the special case of referenda. Yet for all the apparent advantages and efficiencies of indirect representation, this system brings with it certain liabilities. The removal of citizens from the sphere of substantive decision-making can also make people feel powerless. ChoiceWork, which is based on the Kettering Foundation's extensive work on deliberative methodologies, is an attempt to engage communities in directly shaping their futures. It is based on a vision of communities talking together and naming and framing issues in order to build the necessary consensus to solve problems.

Since 1994, community planning has been utilized to identify needs and priorities of HIV prevention interventions in communities across the United States and in Central America. The steps of an HIV prevention community planning process are incorporated into the ChoiceWork approach. Community ChoiceWork will result in an engaged community motivated to take action on issues of concern. The process of coming together around common problems in a safe, non-confrontational environment will change the way people relate to one another. This process can strengthen the bonds within a community and lead to action and changes for this community.

Community ChoiceWork can produce three things: 1) a deeper understanding of the problem at hand, with all its complexities; 2) a community action agenda; and 3) a public voice that is useful for advocacy work and community-driven development. Through the process of deliberating, Community ChoiceWork also facilitates the strengthening of social bonds within a community and addresses the underlying relationships that might have caused the problem in the first place. The stronger bonds can help improve many different aspects of a community trying to address HIV/AIDS.

Throughout the world, HIV/AIDS is affecting communities, regions, countries, and continents. Over the years, most interventions have focused on biomedical and sexual behavior determinants and disease prevention and treatment. Yet, the limited success of prevention has meant that the social consequences of the HIV/AIDS epidemic have been devastating. In addition to prevention, there is a need to focus on how to care for infected populations and how to deal with stigma, discrimination, and the large numbers of people who are sick and dying within communities. Interventions must involve more than biomedical and sexual behavior determinants, taking into consideration the socio-economic environment and macro factors such as wealth, culture, religion, and governance. There are certainly no easy answers, and no one way to address the issue. New theories on HIV/AIDS argue that the degree of social cohesion in a society is one determinant of how many people will be infected and how rapidly the epidemic will spread. Thus, any actions that enhance the degree of social cohesion may help improve prevention, support, and care.

All major players in the fight against AIDS are passionate about carrying out their various agendas. There is a need to broaden the pool of stakeholders to achieve wider acceptance to implement these agendas and to generate new approaches. There is a need to engage those not normally participating in HIV/AIDS issues. Community ChoiceWork creates a link between individual values and policies and programming. It offers an opportunity for people to talk with each other, to share ideas, and to deliberate about how to deal with an epidemic like HIV/AIDS. The ChoiceWork approach can expand the pool of supporters, which will assist in moving forward with policies, programs, and behavior change related to the impact of the disease.

Access to Health Care and Treatment

In the Dominican Republic everyone is concerned about the problems regarding access to health care and treatment for those living with HIV, yet there are many ways to view this problem. Some groups focus on the human rights element, while others look at the governmental budget. Some blame the inefficient health system, while others argue that it is due to an absence of sexual education programs in the schools.

The deliberative process identified four approaches for dealing with this issue: 1) ensure resources to guarantee access to treatment 2) guarantee human rights, 3) integrate the national health system, and 4) provide communication, education, and training.

Community ChoiceWork: Step By Step

Step 1: Getting Started:

ChoiceWork can be used for issues

...on which choices must be made, but there are no clear answers;
...of broad concern within a community;
...on which a range of people and groups must act in order for the community to move forward;
...on which new approaches may allow the community to move forward;
...where citizens have not had the opportunity to consider different courses of action and their long-term consequences;
...about which policymakers' decision-making needs to be informed by public judgment.

ChoiceWork is not useful for problems

...that are highly technical and require a technical solution;
...that need only a yes or no answer;
...for which a specific solution has already been decided and the public's role would only be as a rubber stamp;
...that requires an immediate response;
...that is relevant only to a narrow interest group;
...on which your group has a particular approach to advocate.

Task 1: Agreeing on the Intended Goal for Using ChoiceWork

Outcome: Agreement on Goal

Beginning the Community ChoiceWork process implies that someone wants to work through a particular issue. This may be an individual organization, a consortium, or a collective group of activists. First, the group coordinating the ChoiceWork effort should have a broad issue in mind. The group must also be clear about the objective of the process. The goals could be one or more of the following:

- to encourage community residents to deliberate on an issue
- to motivate community residents to take action on their own
- to help ensure that NGO's own programs are more community-driven
- to gather information from residents for the coordinating group to use in advocacy efforts to affect policy change

All of these objectives are legitimate reasons to use Community ChoiceWork. So as not to create confusion later about who is responsible for taking action based on ChoiceWork outcomes, the group starting the process should be very clear about the goal from the beginning.

Task 2: Ensuring Commitment From the Group Coordinating the ChoiceWork Process

Outcome: Commitment Ensured

The eight-step Community ChoiceWork process involves commitment from many people. First, the leaders of the PVOs, NGOs, or CBOs involved need to give full support to the participatory process and acknowledge that while it may take a long time, the benefits of having a public voice are stronger than moving forward with a plan of action without public support. Specifically, the coordinating group should be willing and able to commit staff time to coordinate, facilitate, network, and convene meetings and, provide administrative support to publicize events, take

notes during meetings, and write reports. It also should agree to act on the public recommendations produced through the ChoiceWork process even if they are likely to result in action that is different from what was originally intended.

A good first step to get started is to hold a workshop with a consortium of organizations and individuals who are dedicated to solving a particular problem. This workshop will allow for an introduction of the ChoiceWork tool and provide an opportunity for participants to apply it to the problem of interest.

Table 2 lists the steps of Community ChoiceWork and the various actors who are responsible for carrying out the tasks.

Table 2
Roles and Responsibilities

Steps	Actions	Time
Getting Started	Organization or group coordinating the Community ChoiceWork effort decides to move forward with the process.	
Stakeholder Analysis	Organization or group coordinating the effort identifies stakeholders and forms the ChoiceWork Committee.	Month One
Mapping and Naming the Problem and Framing Choices	ChoiceWork Committee works with a facilitator (either a trained staff person from the group coordinating the process or someone hired from outside) in an interactive process to map and identify concerns, cluster similar concerns and perspectives, and name the problem and frame the choices.	Month Two
Testing the Framework and Developing a Discussion Guide	ChoiceWork Committee tests the framework through focus groups and interviews and writes a title. Discussion guide is produced.	Month Three
Deliberating and Setting Direction	Group coordinating the process arranges numerous public forums with support from the ChoiceWork Committee.	Month Four
Reporting	Reports from the numerous forums are compiled by group coordinating the process.	Month Five
Creating an Action Plan	The group coordinating the process works with the community to create an action plan based on the reports.	Month Six
Taking Action	The action plan is carried out, monitored, and updated.	Ongoing

Step 2: Stakeholder Analysis Month One

Task 1: Identify Major Stakeholders

Outcome: List of Stakeholders

In the context of Community ChoiceWork, stakeholders are those groups of people representing different perspectives within a community. It is important to identify the wide range of perspectives on the topic to be discussed. Identify different groups of people who are affected by, either directly or indirectly, or might have an effect on the issue being discussed. Breaking down the stakeholder groups by gender, major ethnic groups, locality, and other variables will assist in identifying important groups who may otherwise be overlooked. Key groups may come from the general public, people living with HIV, religious and faith-based groups, businesses, the government, civil society organizations, academic institutions, media, and the private sector.

Task 2: Determine the Importance and Influence of Each Stakeholder

Outcome: Map of Stakeholder Influence

Determine which groups are important to ensure a wide diversity of viewpoints when naming and framing the problem. Some groups may be greatly impacted by the issue being discussed and others may have great influence over the issue.

Task 3: Select Members for the ChoiceWork Committee

Outcome: Formation of ChoiceWork Committee

When broad stakeholder groups have been identified, people who can reflect the experience of each group should be selected to participate on the ChoiceWork Committee. These people should be capable of active dialogue, contributing the perspective of their sector of the community and sharing the information back with others who share that perspective. Ideally, the ChoiceWork Committee should consist of people who can provide perspectives from the business, civic, legal, media, religious, and academic communities as well as people living with HIV/AIDS. The committee should have no more than 12 members.

The first meeting of the ChoiceWork Committee should allow time for team-building and discussion of the objectives and process of Community ChoiceWork. Understanding each member's motivation for participating on the committee and personalizing the issue at hand will be helpful in the long run.

Committee Members

The deliberative process was used in the Dominican Republic to identify ways to prevent crime. A local advertising agency provided the coordinating role with committee members from:

- a community church group
- the media
- a business organization
- a police group
- a group that works with convicts
- a community development organization
- an NGO focusing on education
- an NGO focusing on judicial reform
- an NGO focusing on institutional development issues

Some of these people volunteered while others were invited to participate on the committee. Those who were invited were already working on crime prevention or were considered to be key players in the effort. Although some of the original members left the committee, many suggested replacement members. The final committee is composed of a very committed group of 12 people who actively organize forums and recruit other people for the crime prevention effort.

Step 3: Mapping and Naming the Problem and Framing Choices

Month Two

Task 1: Mapping and Identifying Concerns

Outcome: List of Concerns Related to Issue at Hand and a Tentative Naming of the Problem

Mapping begins with individuals telling their own stories to relate how the problem affects their lives and what they value. This provides the ingredients for defining the problem from the citizen's point of view. Gathering this information requires interviewing citizens and holding focus groups to include as many perspectives on the issue as possible.

An initial workshop for the committee members provides an opportunity for a brainstorming session focused on identifying concerns regarding the issue at hand. Once they have exhausted their own concerns, they should think of people who are not in the room who might have different perspectives and then voice the concerns of those people.

Members of the ChoiceWork Committee should meet with people in the community to discuss the situation at hand to identify its important dimensions, the relationships that cause it, and the interests affected by it. After identifying concerns from people with varying perspectives, the ChoiceWork Committee adds to its original list of concerns.

In addition to identifying perspectives from various communities, the committee needs to gather factual information that is essential to making informed decisions. Factual information on the HIV/AIDS situation should include epidemiological data, successes and challenges of interventions, and behavior change models. The group should also develop an epidemiologic profile, conduct a needs assessment, assemble a resource inventory, and conduct a gap analysis about the situation itself. A literature review of the issue can also be useful.

Semi-Structured Interviews

Semi-structured interviews are informal conversations for gathering information. They are based on a predetermined set of topics, which can be added to and modified as needed. The interviewers prepare a list of questions to use as a general guide, rather than reading questions from a fixed questionnaire. These questions guide conversations with individuals or small groups who are likely to provide information, ideas, and insights on a particular subject. Some general questions might include:
What is the problem? What can be done? Who is responsible? What are your concerns regarding the issue?

Preparations and considerations for structured interviews include:

- preparing the interview guide—the guide is developed based on research questions and issues relevant to the community
- discussing the interview context—the time, place, seating arrangements, body language, and biases are discussed ahead of time
- active listening—facilitators must listen in an attentive, open-minded, non-judgmental, and empathetic manner
- sensitive questioning—facilitators ask open-ended, probing questions
- judging and cross-checking responses—information received from the discussions is evaluated and the facilitators probe further if the responses are not accurate or sufficient
- recording the interview—notes are taken during the interviews

Out of this work should come a tentative naming or definition of the problem. That definition should be broad enough to reflect the main perspectives in the community. Everyone should feel that he or she can relate to the problem as named. That feeling is the beginning of citizen engagement. The tentative name will be reviewed as the work of framing choices is completed, but it is essential to start the framing process with the clearest and deepest sense of what citizens feel the real problem is.

Clustering Concerns

Using comments from more than 100 email messages regarding HIV/AIDS–related stigma, the clustering process took time. It was necessary to distill information from lengthy personal stories into tangible concerns with driving principles. While the stories were unique and shared different aspects of HIV/AIDS–related stigma, it was possible to identify some underlying principles:

1) stigma needs to be overcome in the home environment;
2) stigma should be treated as a human rights issue; and
3) overcoming HIV/AIDS–related stigma can only happen if the disease is normalized.

Task 2: Grouping Like Concerns and Perspectives

Outcome: Clusters of Concerns Grouped Into Three or Four Approaches

The ChoiceWork Committee reviews the list of concerns. It is helpful if each concern is listed on a separate sheet of paper. Look for the underlying worries or convictions. Most likely there will be particular principles that run through a significant number of the concerns. Cluster these concerns together by grouping the pieces of paper on the wall together. The unifying principles will form the basis for potential approaches to addressing the issue. Once there is a manageable list of approaches, write a sentence or two that clearly captures the essence of that perspective.

Task 3: Recognizing the Tensions

Outcome: Agreement on Tensions Among Choices

Once the problem and various perspectives on how to view it have been validated by the broader groups, the ChoiceWork Committee meets to probe the dynamics of the problem in order to frame potential choices for dealing with it. These choices are not framed as technical solutions, but rather by what the citizens value in terms of actions they feel are necessary. The framing should capture the tension among choices. Not everyone will agree with each approach, but everyone should be able to agree on the existence of the motive that drives it. At the same time, the approaches should capture the different, and sometimes conflicting, ways to deal with the issue. Some characteristics of a well-framed issue include:

- Approaches are distinctively different, not just opposites of each other.
- Approaches are persuasive enough so that they pull against each other; each has some appeal for different interests.
- Each approach is presented "best-foot-forward" and aspects of it might appeal to anyone.
- Each approach captures something valuable to people.

Task 4: Listing Actions

Outcome: List of Actions for Each Approach

Since the ultimate purpose of public deliberation is to enable people to make sound choices about how they are going to act, there must be concrete and specific steps posed for each approach. The course of action might include things citizens or groups of citizens should do; efforts by government agencies; or efforts by other institutions, such as businesses, schools, and religious and faith-based organizations. If the committee finds it difficult to list actions that correspond with a particular approach, then that approach may not be strong enough to stand on its own. It may simply belong as part of another approach. To identify a list of actions, it helps for the committee to ask: "If you were a person who believed that this approach is the best way to deal with the issue, what would you say needs to be done? Who needs to do what?"

Task 5: Outlining the Benefits and Drawbacks of Each Approach

Outcome: List of Benefits and Drawbacks of Each Approach

Look again at each approach and the list of actions consistent with that approach and list the drawbacks or negative consequences associated with implementing this action. First, identify at least five reasons for tackling the issue from each approach. Next, identify the consequences of taking each approach. This is not a matter of debating the pros and cons of each perspective, but rather the benefits and trade-offs associated with each. For deliberation to occur, people must weigh the consequences of an approach against what they hold valuable. The consequences can be philosophical or material.

What is the REAL problem?

In the Dominican Republic ChoiceWork training, the participants began with an assumption that they were going to deal with the problem of people living with HIV not having access to anti-retrovirals. In going through the deliberative process of naming concerns, clustering the perspectives, and recognizing the tensions, they discovered that the problem was much broader. They expanded the issue to "Access to Health Care and Treatment for Those Living with HIV."

Task 6: Naming the Problem

Outcome: A Statement That Describes the Common Problem

Now is the time to review and refine your tentative naming of the problem in light of insights gained from the framing exercise. Identify the thread that runs through the list of potential approaches. Do they really address the common problem that we tentatively identified? Can we do a better job now of stating what this problem should be called? Write a fuller statement now that describes the common problem most accurately for the full range of concerns.

The ChoiceWork Committee members then share this information with others from their sector within the community to validate the statement and clusters of approaches. If the broader group feels that their interests are not reflected in the statement and approaches, the ChoiceWork Committee may need to meet again to work through the clustering and naming of the problem.

Step 4: Finalize the Framework

Month Three

Task 1: Testing the Framework and Writing A Title

Outcome: Framework and Title Written and Validated

With the actions, benefits, and trade-offs in place for each choice, there is a fully framed issue. If there are more than four choices, then the committee will need to take some more time to combine ones that are, at their core, about the same kind of beliefs and concerns and reexamine whether any of the approaches are actually addressing a different problem. The committee members should report back to the community to validate the framework.

- Does the naming statement of the problem still match up with the approaches? Does each approach address that problem directly?
- Does the framing reveal what people hold valuable? Are the motivations that underlie the different points of view understood?
- Does the framing of the issues give direction for action?
- Are there realistic actions consistent with the philosophy of the approach?
- Does the framing put the "best-foot-forward" for all approaches?
- Are trade-offs, costs, and drawbacks clearly spelled out for each approach?
- Is there a balanced tension between the approaches as now written?

The committee should hold some focus groups and test forums in communities using the framed issue. They may also want to hold short workshops with different groups to name and frame the same issues to see what types of differences arise. Once the framework is validated by the stakeholder groups, the final task is to put a title on the framing. The title should describe what is at issue and be inclusive of the different points of view. Generally, it is a good idea to pose either the main title or the subtitle as a question that draws everyone into the conversation. It is also a good idea to write a title that reinforces the idea that citizens are actors in the political process and they are an integral part of any kind of community response to a problem. For example, HIV/AIDS: What should we do about stigma?

What if members of my community can not read the discussion guides?

In many cases the written guide is not a central focus for discussion. The forum moderator lays out the various perspectives orally. Visual methods that have been used to demonstrate the different perspectives include short drama performances or videos.

Task 2: Write Discussion Guide

Outcome: Discussion Guide Produced

The discussion guide is usually divided into three sections. First, provide a neutral overview of the issue being discussed. Second, describe the approaches one by one. For each approach, first outline the point of view of people who believe in this approach, then list actions that could be implemented under this approach, and finally list some of the trade-offs that come with taking these actions. The final section of the discussion guide focuses on what was learned in the forum. Questions for reflection include: What did we learn? Where do we agree? Where do we disagree? And, What might we do? (See Appendix A for illustrative discussion guides.)

Step 5: Deliberating and Setting Direction

Month Four

Task 1: Coordinating Public Forums

Outcome: Forums Arranged and Publicized

The group coordinating the Community ChoiceWork effort needs to take the lead in organizing numerous public forums for community residents to deliberate the issue that has been framed. Members of the ChoiceWork Committee should assist in reaching different populations. Ideally, many forums would be held in various communities during a designated period of time. The best way to get people to participate in forums is for a trusted person to invite them. Thus, in addition to broad publicity for the forums, relying on support from trusted community members can ensure a successful turnout.

Prepare each detail for hosting the forum. Copies of the discussion guide should be available for each forum participant. There should be a facilitator, a note-taker, and possibly an observer. The chairs should be arranged in a circle, and there should be flip-charts, markers, and tape. You may also want food and beverages available.

Forums or Study Circles

Many conveners choose to organize single forums around issues of concern in their communities. Most single forums last two to three hours. Many others, however, arrange multiple sessions, or study circles, to allow participants greater opportunities to examine issues in depth. Some groups set aside time for two meetings, others might devote a separate session for each choice. And some plan ahead of time for a session after the forum to come back together to consider next steps. Some communities begin their examination of an issue in a large group forum and then break off into smaller groups for subsequent sessions. The reverse can also be helpful—starting in small groups and culminating in a larger community forum. The needs of your community will help determine the most conducive format for deliberation.

Task 2: Moderating Public Forums

Outcome: Forums Held

The next step involves holding the forums to deliberate the issue. The forum is moderated by someone trained to facilitate a deliberative dialogue. The moderator in a deliberative forum is very important. This person must ensure that the appropriate mood of the discussion is maintained and that the direction of the discussion stays on track. This person may be a leader or a staff member of the organization coordinating the process, or an outside facilitator. The forum works through the problem and the various approaches that were identified in the earlier steps. Each option is discussed independent from the others, so that all choices are given as full a consideration as possible. The moderator's purpose is to create opportunities for each participant to consider deeply how this problem affects others who may have had a seriously different experience. The objective of the forum is to move toward a sense of direction or even a public decision through an understanding of the benefits, costs, and consequences of each option, and knowledge of the strategic facts and how they affect the way the group thinks about each option. There should be a progression from first reactions and mass opinions toward a more shared and stable public judgment. Full agreement is probably not a realistic objective, but enough sense of common ground can emerge to provide a starting point for beginning steps toward improving the situation.

In general, a forum format will be as follows:

1. Welcome—moderator introduces the program.
2. Set ground rules—participants review desired outcomes of the forum and agree on guidelines. For example:

Role of the Moderator

- To provide an overview of the process of deliberation—the rationale for the kind of work the participants are getting ready to do.
- To ask questions that probe deeply into what's at stake in the issue and in each choice.
- To encourage participants to reflect on others experiences and direct their responses and questions toward one another.
- To remain neutral throughout the discussion, while encouraging participants to explore all facets of their own and others' opinions.
- To keep track of time, so participants can move through a discussion of each of the major approaches and into an ending period of reflections.

Facilitating Discussion and Managing Conflict

- Make everyone feel comfortable and valued
- Encourage participation
- Listen and observe
- Guide the group
- Ensure quality decisions
- Ensure outcome-based meetings
- Prevent and manage conflict
  - Make sure all sides have an opportunity to be heard
  - Help to clearly define the issues
  - Keep discussion focused on the substance rather than the individuals
  - Help individuals to save face and be able to change their position

- Everyone is encouraged to participate.
- No one or two individuals dominate.
- The deliberation will focus on the approaches as laid out in the discussion guide.
- All of the approaches are considered.
- An atmosphere is maintained for deliberation and examination of trade-offs among approaches.
- Everyone listens to each other.

3. Starter discussion—moderator presents the issue at hand and the different approaches. Show the video or perform the drama describing the issue and approaches, if these have been developed.
4. Discuss personal stake—as an icebreaker, participants tell personal experiences related to the issue. Questions to ask include:
   - How has this issue affected you personally?
   - How did participants come to hold the views they have?
5. Deliberation—participants examine all the approaches. Specific questions to be asked when examining each approach include:
   - What are the costs and consequences associated with each option?
     - What would result from doing what this option proposes?
     - What would be the best argument against the option you like best?
   - What are the tensions or conflicts in this issue that we have to work through?
     - What do you see as the tension between the options?
     - Why is this issue so difficult to decide?
6. Reflection—identifying the public voice and action priorities.
   - How has your thinking about the issue changed?
   - How has your thinking about other people's views changed?
   - Can we detect any shared sense of direction or any common ground for action?
   - What did you hear the group saying about tensions in the issue?
   - What were the trade-offs the group was willing or not willing to make?
   - What do we still need to talk about? How can we use what we now know?
   - What action do we want to take? What are the priorities?

Setting Direction

In a small town in Puerto Rico, a consortium of community-based organizations concerned with the economic health of the region used the deliberative process. This consortium had been trying for many years to develop a series of corporations that were economically viable and could run educational and community development projects. The deliberative process helped the members of the consortium working in each of the corporations realize that they were trying to do too many things at the same time—an inefficient and ineffective way of achieving their goals. The group made a commitment to maintain an ongoing dialogue to reflect on their practices and to concentrate their money and efforts into making one of the corporations successful enough so it could financially assist the other projects and corporations in the future.

Task 3: Setting Direction In Public Forums

Outcome: Forum Participants Set Direction

By the end of the deliberation, the participants may identify common ground from which they can move to action. It does not signify total agreement. The goal is to develop a sense of what their common aims are and what is tolerable and intolerable for each significant actor, and why. If they cannot do this in one meeting—and they may well be unable to—it will be worth inviting them to continue their dialogue in follow-up meetings until some common ground begins to emerge. They will then begin considering their commitments to engage in the common task of dealing with the problem at hand.

Step 6: Reporting Back
Month Five

Task 1: Taking Notes During Forums
Outcome: Forum Summaries

Throughout the forum, a note taker should have been keeping track of what was said and the decisions that were made. While the note taker identifies the factual information from the discussion, it may also be useful to have an observer who reports on the emotions and atmosphere of the forum. The note taker and observer should combine their findings to write a full report for the group or organization hosting the Community ChoiceWork process as well as for the participants of the forums. It is also a good idea to validate the report with the forum participants, if possible. This would involve sharing the report with the participants and getting feedback.

Role of the Note Taker

- To support deliberation by reminding forum participants of their key concerns, the areas of greatest disagreement, and the benefits and trade-offs their discussion highlighted.
- To provide a written record of the group's work that might feed into future meetings of the group or additional forums.
- To help inform other members of the community about the outcomes of the deliberation.
- To capture the tensions, trade-offs, and common ground for action.
- To express main ideas in clearly written, brief phrases.

Task 2: Compiling Reports From All Forums
Outcome: Final Report

The group or organization hosting the process should compile one report based on the findings from all forums. This report can then be used to move forward with an action plan.

Based on the goals stated at the beginning of the process, a number of actions may occur. It should have been clear from the start what the primary objectives would be: community mobilization, program design, or advocacy. Step 7 identifies the steps to take for creating action plans for these goals.

Preparing a Report

If you are preparing a report from a deliberative forum for groups of political leaders, generally concerned citizens, special interest organizations, or the media, you will need to bear these in mind:

1. Use a variety of methods (observe forums, interview moderators and participants).
2. Analyze a minimum of six forums.
3. Don't let the analysis interfere with the forum process.
4. Don't confuse analysis with recording.
5. Use one or two observers/authors, working together.
6. Review preliminary conclusions with people who were present.
7. Compare and contrast results to national reporting.
8. These are not poll results and lack statistical precision.
9. This is a report of people's thinking -- the values and considerations people draw on as they deliberate about a complex issue and consider various alternatives or choices for dealing with it, along with the accompanying trade-offs.

Step 7: Creating An Action Plan

Month Six

Goal: Community Mobilization

Outcome: Community Creates Action Plan for Themselves

Making choices together in deliberation promotes civic responsibility. The individuals deliberating may be ready to take more responsibility for the actions they have identified as the best way to move forward. Deliberation allows people to do things they couldn't do as isolated individuals. While the deliberation may not end in total agreement, it can point people in a particular direction and give them a foundation for identifying shared or interconnected purposes.

The deliberative process may have successfully engaged the community so that it has become energized to work together on a small aspect of the issue. Or, during their next-step discussions, participants may have agreed to hold more deliberative forums. The group coordinating the process can encourage and facilitate these actions.

After months of working together, the members of the ChoiceWork committee should have developed a good rapport. The group or organization coordinating the process might want to encourage the committee to continue working together on other issues.

Steps to take to stimulate complementary action include:

- Identify shared purposes out of the many reasons people have for responding to a problem that affects each of them personally, yet in different ways.
- Diagnose the obstacles that stand in the way of our working together to deal with the serious problem. Identify steps to overcome those obstacles and who might take such steps.
- Develop a sense of interdependence, a sense that even though my purposes and interests are different, I can't get what I want without your help. This sense leads to devising more effective, mutually reinforcing ways of working together.
- Identify inherent capacities, the resources and power that come from each person's unique talents and can be expressed through everyday activities.
- Join capacities so that the whole of individual actions can be greater than the sum of the parts. Joined capacities create a sense of possibility and inspire public action. Joined capacities that serve shared purposes result in an array of actions that reinforce one another and generate a sense of momentum.

Goal: Community Priority Setting for Action
Outcome: Community Prioritizes and Designs Programs To Be Carried Out

As noted earlier, the ChoiceWork approach is similar to several other community-involvement processes that are being used in a variety of settings. Most notably, ChoiceWork shares many common elements with the HIV prevention community planning process used in the United States in conjunction with the Centers for Disease Control activities. The first five steps of that community planning process, for example, have been incorporated into tasks covered in this manual. Step six of the community planning process—prioritize populations and interventions, should occur during the deliberation and direction-setting stage of the ChoiceWork approach. We need to establish priorities—a ranking of choices that reflects our sense of what's important to be done in our communities. HIV and AIDS is a complex issue with many potential avenues to explore. Yet without prioritizing specific steps, we will be pulled in many directions and probably will not successful in directing our time and energy to specific accomplishments.

Setting priorities in terms of HIV prevention means identifying the most important target populations and the interventions you recommend for them. It is based on the information gathered through the ChoiceWork process. Once you have identified and defined target populations, the group needs to determine factors, or criteria, that will be used to compare each population. Then the factors must be weighted—that is, assigned a number in terms of importance. The group should then rate and score the target populations using the chosen factors and weights. Based on these scores, the target populations can be ranked. Review the rankings and prioritize the target populations. Use the same process to rank and prioritize the interventions for each target population. Your action plan should be based on these priorities.

Goal: Advocacy Campaigns
Outcome: NGOs Work with Community to Plan Advocacy Campaign

In addition to mobilizing the community to action, the ChoiceWork process should have generated useful information for the coordinating group. The reports from the forums will indicate a common public voice on a particular issue that can assist in advocacy directed at changing the policies, positions, or programs of any type of institution.

Advocacy is a process of making sure that your national and local government, your elected representatives, and your local institutions serve your needs as well as possible. Effective advocacy may succeed in influencing policy decision-making and implementation by 1) educating leaders, policymakers, those who carry out policies as well as fellow citizens; 2) reforming or monitoring existing policies, laws and budgets, and development programs; or 3) creating more democratic, open, and accountable decision-making structures and procedures. The basic elements of advocacy include:

- identifying a problem and finding a possible solution
- deciding who you need to convince to make the solution a reality
- using research and factual information to convince decision-makers and others that your solution can work
- identifying allies and possible partners
- developing and delivering your message to decision-makers and fellow citizens
- building coalitions
- convincing others by making persuasive presentations and obtaining media coverage
- fund-raising to support your efforts
- evaluating advocacy efforts

The advocacy process is dynamic and involves an ever-changing set of actors, ideas, agendas, and politics. This process can be divided into five fluid stages: issue identification; solution formulation and selection; awareness building; policy action; and evaluation.

The implementation of this process requires increasing interaction among NGOs, citizens, local government, and other state or local institutions in order to improve their functioning. It frequently also involves interaction with the local private sector.

The ChoiceWork process incorporates the first three stages of the advocacy process. Building awareness of the issue must continue after the forums are held to bring information from the forums to policymakers. Additional steps that should be included in the action plan are to:

- understand decision-making processes
- understand audiences
- build alliances and networks
- refine presentation techniques

Step 8: Taking Action

Now that everyone is on board with the action plan, it is time to carry out the proposed activities! Groups implementing action plans should track and keep records on an ongoing basis to evaluate the effectiveness of the action and to periodically update the plan.

Assessing the impact of the activities depends on performance monitoring and evaluation. Performance monitoring is the ongoing process of collecting and analyzing data to measure the performance of a program, process, or activity against expected results. By continually assessing performance, the group will acquire the knowledge and understanding needed to adjust activities to optimize achievement of results. Lessons learned will contribute to improvements for future programs and strategies. An evaluation, on the other hand, is a relatively structured, analytic effort undertaken periodically to answer specific questions regarding programs or activities.

Together, monitoring and evaluation are used to:

- assess progress in achieving goals
- identify corrective action needed to achieve goals
- build the capacity of participants to reflect, analyze, and take action
- ensure financial accountability
- provide organizational credibility and garner public support

While an outsider (not associated with the program or activity) may conduct some evaluations to obtain an objective, third-party viewpoint, most evaluations can benefit from a more participatory approach. A participatory evaluation complements the ChoiceWork approach because it involves the collective examination and assessment of a program or activity by stakeholders. In participatory evaluation, activity stakeholders are the key actors in the evaluation process, not the objects of it. Involving various actors in planning, conducting, and interpreting evaluation findings will ensure that data will be collected and used in ways that will meet the needs of everyone involved.

A participatory evaluation:

- provides participants with the opportunity to reflect on an activity's progress and obstacles
- identifies differences in perspectives held by various participants and analyzes their reasons
- generates knowledge that participants can use to change activities to maximize results
- provides participants with the tools to transform their environment
- builds evaluation capacity in participant organizations or groups

The completion of an evaluation often is the beginning of a new stage in the development process, not the finale. This important phase links the evaluation back to planning. By taking time to reflect on the evaluation findings, conclusions, and recommendations, the participants may also gain additional insights, which in turn may lead to further actions.

Appendices

Appendix A
Illustrative Discussion Guides

The Community ChoiceWork process described in the main text of this manual will help groups work with community members to name and frame an issue to create a discussion guide for deliberating a problem. The illustrative guides below are intended to give readers a feel for what their discussion guides might look like. These would not be the best guides to use for an actual forum since the information should be framed in the local context. The content and approaches will most likely differ from group to group.

The information in the first guide on how to overcome HIV/AIDS-related stigma was gleaned from more than 100 messages posted on the Health and Development Networks' electronic discussion on stigma and HIV/AIDS. More than 1000 people participated in this electronic discussion that took place between March and August 2001.

The second illustrative guide was developed during a Community ChoiceWork workshop in the Dominican Republic. Twenty HIV/AIDS activists spent three days going through the ChoiceWork process. This guide is one outcome of their training. It represents a first cut at framing the issue of access to health care and treatment for those living with HIV in the Dominican Republic.

HIV/AIDS: How Can We Overcome Stigma?

HIV/AIDS–Related Stigma

Stigma, silence, discrimination, and denial undermine prevention and care strategies and increase the impact of the HIV/AIDS epidemic on an individual. Stigma negatively affects the potential contribution individuals and families can make toward prevention of HIV/AIDS and is one of the key obstacles to accessing care for people and families affected by this pandemic.

HIV and AIDS–related stigma can appear in a variety of contexts. These include the family and the community, education and the school, employment and the workplace, hospitals, clinics and health care systems. Additionally, people with HIV may be stigmatized in relation to travel, migration, and immigration. National and local AIDS programs have sometimes reinforced stigma by prioritizing work with certain groups while underplaying the importance of work with others.

The dictionary defines stigma as "a mark or sign of disgrace or discredit; a distinguishing mark or characteristic; a visible sign or characteristic of a disease." Stigmatization describes a process of devaluation. It is linked to power and domination in a community as a whole. People who are stigmatized by others may be cut off from society and the community; they may be shunned by their neighbors and talked about behind their backs; they may be denied access to resources they need to live their daily lives.

Stigma is a result of lack of knowledge, misinformation, and fear of the unknown. In addition, in the case of HIV, the incurability of the disease easily translates into a stigma of the disease. Stigma is a perceptual phenomenon—stemming from both real and imaginary perceptions of the disease. There seems to be more perceived stigma than what is actually experienced. This results in a climate of fear and apprehension.

AIDS–related stigma is linked not only with the fear of the virus, but also can be associated with a series of assumptions relating to class status, sexual morality, hygiene, gender, ethnicity, and so on. HIV thrives in a climate where people with HIV/AIDS face blame, discrimination, and stigma. Effective prevention and care of people with AIDS depends on deep-seated social change within societies. Instead of socially isolating people with HIV, they should be encouraged to take a leadership role in education and prevention.

Attempting to understand stigma—where it comes from and how to overcome it—generates numerous opinions and suggestions. This discussion focuses on three approaches to overcome HIV/AIDS–related stigma.

1. Overcome stigma in your home environment.
2. It's a human rights issue—the law is on your side.
3. Normalize the disease—model non-stigmatizing behavior.

Approach 1: Overcome Stigma In Your Home Environment

Point of View

Stigma starts with oneself. It begins with an individual not seeing the benefit of living and feeling ashamed. Self-stigma is pronounced by fear of how other people will relate to him/her. For instance, many do not call on home-based care volunteers until the last stages of AIDS—not because they can't afford it, but because they fear the reactions of neighbors when they see the home-based care truck in their front yard. Most have children and other family members to support and do not want them to be shunned because of their sickness. People will withdraw for fear of being judged, ostracized, or shunned.

If a person can overcome the fear of having others know that he/she is HIV positive, then others will be better able to deal with the knowledge because it can be discussed openly. Although the press often sensationalizes stories about how families and communities have shunned people who have shared their HIV status, the reality is quite different. Families and communities show great humanity in the way they care for people who have become sick.

Actions

Disclosure is the best tool to deal with stigma. Begin by accepting your situation and being prepared to understand other people's reactions. Demystifying the disease can do this.

First, overcome self-stigma. People need education about the nature of HIV and what can be done to live longer with the virus. This will remove much of the fear of HIV and give many the courage to get tested. Through counseling and by teaming up with other people that are HIV positive, individuals can come to terms with their status and start to actively adopt a lifestyle that can prolong their lives. By meeting with other people in the same situation, a person can realize that there is nothing to be ashamed of and certainly nothing to feel guilty about. When a person has accepted his HIV status and started to take control over the virus in his body, he has dealt with the first level of stigma.

Second, overcome family stigma. Overcoming a sense of stigma in oneself is the first step toward sharing with family and community members. Once families and friends see that the individual has come to terms with the diagnosis and is getting on with his/her life, they will learn to do likewise.

Third, overcome community stigma. Normalize HIV/AIDS within the community by informing and discussing the subject again and again, stimulating care activities to be taken up by communities themselves, and

always addressing prevention and care together. Educating the community through peer education has proven to be quite successful. Providing a forum for people to give testimonials about their HIV status has been proven to increase the number of people willing to have an HIV test. Create supportive environments where people can tell each other that they have been tested without embarrassment, shame, fear, or judgment.

Dangers, Drawbacks, Trade-Offs

Should everyone be open about his or her status? No, if a person is in a vulnerable situation, such as having no support, risking losing a job, losing a home, or even losing children, overcoming stigma at home can only take a person so far.

Approach 2: It's A Human Rights Issue—The Law Is on Your Side

Point of View

Stigma does not just happen. It builds on and reinforces people's prejudices, is linked to power and domination in communities, and is created and reinforced by social inequality. So long as issues remain at the level of negative thought—stigma—no harm is done to others. However, once a person's prejudiced thoughts leads him/her to do something, or fail to do something, he/she is harming or denying services or entitlements to another person. This is a discriminatory act.

Discrimination occurs when a distinction is made against a person that results in him/her being treated unfairly and unjustly on the basis of his/her belonging, or being perceived to belong, to a particular group. Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. The basic characteristics of human rights are that they inhere in individuals because they are human and that they apply to people everywhere in the world.

Some people argue for a human rights approach to combating AIDS-related stigma. Arguing that principles of non-discrimination are central to human rights, they believe that HIV-related stigma should be combated within a human rights framework. Rather than create new mechanisms for addressing stigma, existing procedural, institutional, and other monitoring mechanisms for enforcing the rights of people living with HIV/AIDS and for countering and redressing discriminatory actions should be used. When using these mechanisms, the structural and environmental context in which individuals and communities operate as they respond to HIV and AIDS must be taken into consideration.

Actions

The human rights process gives access to existing procedural, institutional, and other monitoring mechanisms for enforcing the rights of people living with HIV/AIDS and countering and redressing discriminatory action. Since discrimination leads to legal offences being committed, persons who discriminate can be made accountable by law and redress can be provided where appropriate. Specific actions might include monitoring abuses, lobbying for laws, establishing legal clinics, etc.

Dangers, Drawbacks, Trade-Offs

The law and human rights are important tools in addressing both stigma and discrimination. However, law is not an end in itself. It must be supported by the values and expectations of a society as a whole, and these expectations and values are exactly what can also lead to stigma. For society to embrace a law, its members have to be participants in its development — they have to understand it and be able to enforce it. Thus, unless there is an interaction between the law and the cultural and social values, the fundamental changes required to alter the course of the epidemic remain unattainable. Merely focusing on outcomes (discriminatory acts) without addressing the attitudes that give rise to such acts will not work.

Approach 3: Normalize the Disease— Model Non-Stigmatizing Behavior

Point of View

Societal leaders need to set an example by modeling non-stigmatizing behavior. When people see politicians, religious figures, and members of the medical profession normalizing HIV/AIDS, then stigma related to this disease will end. The media has a key role to play in showing images and telling stories that normalize, rather than sensationalize, HIV/AIDS. By demonstrating behavior that stigmatizes (covertly or overtly), politicians, religious figures, and health workers send a message that something is wrong with people who are living with HIV or AIDS. Changing this behavior and emphasizing the normalcy of HIV/AIDS through the media will go a long way to end stigma.

Religious communities are a powerful medium for breaking the silence on HIV/AIDS. Not having been engaged in mainstream AIDS prevention work, they have often failed to expand their traditional care and support for the sick, the poor, and the handicapped to persons living with HIV/AIDS. Believing that infected people are "sinners" has reinforced denial and stigmatization of persons living with HIV/AIDS and persons affected by AIDS. However, when properly engaged, religious communities are willing

and able to respond to the AIDS pandemic. Religious leaders can use their representative role to teach communities methods of AIDS prevention and care and to build a self-supporting community.

In the absence of an effective medical cure for AIDS, education, information, and communication have become critical particularly in breaking down myths, beliefs, and practices that fuel the spread of HIV as well as in challenging irrational ideas and behaviors–like stigma. The media keep society fully informed and educated so that citizens can make responsible and informed choices rather than act out of ignorance. Thus, the media play a key role in providing basic information about AIDS stigma, encouraging discussion about ideas, beliefs, and myths about AIDS; providing opportunities for an open exchange of opinions and views about AIDS, and promoting awareness of how stigma affects the community and prevention efforts. By presenting true facts about HIV/AIDS, media can help eradicate stigma. Also, documenting stories and dialogues of hope from those testing HIV negative can be used as a mechanism for normalizing HIV.

Actions

Within the medical profession, develop clear hospital policy on issues related to the management of HIV-positive clients. Disseminate the policy to the department level and provide clear practical guidelines to hospital staff. This includes normalization of HIV, taking counseling seriously, and providing staff time, space, and support to implement services. In addition, the hospital should encourage all health staff to know their serostatus and facilitate an anonymous service that includes follow-up care support for infected staff. Stigma-reducing interventions should start with health workers being able to provide services to people living with AIDS without fear of touching their skin or coming close to them. There should be further training of health care workers to address attitudes and myths and misconceptions.

In many places, despite compassion shown to the people suffering from AIDS, religious leaders have difficulty hiding their negative attitudes about how the disease is acquired, thereby stigmatizing the very people they claim to care for. There is a need to educate religious leaders on the issues of HIV/AIDS so they can convey the message to their congregations. They should also set an example by taking HIV tests and counseling people.

AIDS journalism often falls short because it fails to integrate the following three elements: 1) the perspectives of people living with HIV/AIDS; 2) the larger cultural, economic, and political context that shapes the epidemic; and 3) the science of HIV. Emphasizing one over the other can create misunderstanding. The most effective journalism weaves together these three elements together.

Media professionals need training in the areas of health and development and in the use of HIV/AIDS terminology. In addition, editors, as gatekeepers, need education and sensitization about HIV/AIDS. They need to be made aware of the implications of inappropriately negative public media coverage and the devastating effects that it can have on the general public.

Dangers, Drawbacks, Trade-Offs

This approach depends on other people changing behaviors. No matter how much training is given to some people, they will not change their minds. You can not convince all leaders to not discriminate. And, even if you could, their model behavior would not put an end to discrimination. Feelings of shame and human rights violations would persist.

Health Care and Treatment: How Can We Ensure Access for Those Living With HIV?

Concerns Regarding Access To Health Care and Treatment for Those Living With HIV

As men and women of the Dominican Republic, we are very concerned about the more than 150,000 citizens, mostly working adults and children, who are affected by HIV/AIDS. Due to this situation, thousands of children have been orphaned, homes have been ruined economically, and the death rate has increased—all of which threatens the growth and development of the country. This problem is made even worse by the fact that people do not receive adequate treatment, given their poor health.

Although everyone is concerned about this problem, we do not necessarily see the problem in the same way. Some of us focus on the human rights element (the right to life, health, and education); others are looking at the precarious governmental budget. Some consider the problem a result of an obsolete and inefficient health system; others argue that it is a result of inadequate education, information, and communication due to the absence of a sexual education program in the schools.

We all agree that the solution is complex, and a solution will not depend entirely on the government, or infected people and their families. Nor can we depend on international assistance to solve the problem.

This guide and the complementary deliberative forums around the country make it possible to begin a national conversation about this topic. We put forth four approaches to guarantee better treatment for those living with HIV.

Your opinions and thoughts, as well as those from members of your community, governmental representatives, and NGO representatives are very important in defining and adopting public policy that tackles this problem. PARTICIPATE!

Approach 1: Ensure Resources To Guarantee Access To Treatment

Those who put forth this approach believe that guaranteeing a specific amount of the national budget would ensure HIV/AIDS patients access to treatment.

Action

The national government would allocate a certain amount of money to ensure that a specified number of people were always treated. If HIV/AIDS becomes part of the national budget, then the treatment would be institutionalized through the law and could not be cancelled by new ministers.

Advantages

- Better coverage.
- It is easier to look for other types of assistance in other sectors once the national government commits to provide funds.
- In the long run, it is cheaper because the government can buy medicine in large quantities.

Disadvantages

- Some say that funds should not come from the national budget, rather from loans and donations. These funds should be dedicated to AIDS issues and not "pedagogical tourism."
- Financing does not guarantee access; other countries have provided access to treatment and not everyone uses it.
- Financing does not guarantee that everyone who has access to treatment will use it responsibly.
- In the DR, we don't even have the essential medical treatments, to think that special treatments will become available through the state is unrealistic.
- It is more efficient to invest in prevention than to invest so much money in treatments that don't cure patients and that need an advanced health care infrastructure, something the DR does not have.
- There are other sicknesses in the DR that kill more people, and they are not allocated money from the national budget for treatment.
- Even when money is designated to treat a specific disease, the secretary of health uses the money for different purposes.

Approach 2: Guarantee human rights

Those who espouse this opinion argue that not providing anti-retrovirals (ARVs) in a sustainable and equitable manner is a violation of the human rights of those living with HIV/AIDS.

Action

- Promote human rights campaigns through media.
- Teach people about the right to patient access.
- Promote an AIDS law.
- Train HIV/AIDS patients to defend their rights.
- Create institutions/mechanisms that allow people to denounce violations of human rights.

Advantages

- ARVs improve the quality of life for those living with HIV/AIDS.
- In terms of human rights, this proposal would reduce discrimination.

- ARVs will improve the self-esteem of patients and their families.
- ARVs reintroduce patients to a productive and social life.

Disadvantages

- Too costly for a poor country.
- This country does not have the infrastructure or human resources for ARV use.
- There are other, more important priorities in the health sector that should get additional financial, human, and technical resources.
- It is necessary to prioritize other groups.
- The health system does not only discriminate against those with HIV/AIDS; it discriminates against the entire population.

Approach 3: Integrate the National Health System

Those who espouse this view understand that the problem of access to health care and treatment is based on a weak health care structure. This is due to the weak health policies that cannot define, respond to, and resolve the political or technical elements of the problem. Other issues, such as limitations of health care providers and the absence of a regulatory mechanism to enforce the general health law and the social security program, reinforce the problem.

An integrated health care system should include services, prevention, assistance, and respect for the lifestyles of both users and providers. These programs should show respect for all human rights, such as ethnicity, gender, sexual orientation and preferences, nationality, language, religion, age, and all others.

Action

- Train human resources.
- Equip health care providers with adequate offices, machines, laboratories, etc.
- Integrate national care.
- Train ministry personnel.
- Develop norms regarding clinical attention.
- Choose adequate protocols.
- Provide proof of monitoring and follow-up.

Approach 4: Communication, Education, and Training (CET)

Those who believe in this approach argue that CET are essential components of better service and lead to the empowerment of those infected or affected by HIV/AIDS. Some argue that the limitations of the health care providers are due to ineffective educational and training programs. Others believe that in order to guarantee efficient use of medicine by the user those who are affected or infected by the disease need adequate information.

Action

- Train health care professionals to attend to HIV/AIDS patients.
- Develop educational materials to train those who are infected and affected.
- Facilitate the distribution of information regarding health care centers.

Disadvantages

- Health care professionals are resistant to treating HIV/AIDS patients.
- It might increase promiscuity, and therefore increase the risk of infection.

Appendix B
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The International Civil Society Consortium
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The Kettering Foundation
www.kettering.org

National Issues Forum
www.nifi.org

PASCA
www.pasca.org/

Projects of the Futures Group
www.tfgi.com/projects.asp

USAID Population, Health & Nutrition
www.usaid.gov/pop_health